

# **Gift of a Lifetime**

**Finding Fulfilling Things  
in the Unexpected**

**Sue Batton Leonard**

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## **Author Statement**

Through my writing of this book I have tried to recall as accurately as possible, anecdotal moments which effectively tell the story. However, I rely on my memory. Memory is fiction. What I was told as a child may be different than an adult's perspective and reality. I look back on those childhood moments, now as an adult, knowing that my understanding may not be exactly correct. Since I can not go back and reconstruct my life, I must rely on my recollections.

Family names are accurate, yet other characters names have been slightly altered, but they are based on real people and events. There are no composite people.

## Preface

A red plaid book bag, a tin lunchbox, stiff leather saddle shoes, white Bonnie Doone bobby socks that sagged and wrinkled like the skin of a Shar Pei dog around my frail and toothpick like ankles are some of the first memories of my life. I can only imagine the thoughts of my mother standing and waiting for the school bus, with my twin sister and me, on that first day of elementary school.

Then, there was my absence of several months from school. What came just before and after that interruption were lots of visits to a foreign speaking doctor from Iran and repeated electrocardiograms. Memories of my first six years of life evade me. It is as if my life began at age seven.

Even as I write this book, I have chosen not to delve very deeply into my first six years of living on this earth. I don't find the sense in it. You'll gain an understanding of this remark as you read along. What is described in this book is only my basic understanding of the chain of events. I've asked few questions and have not gotten mired in the details--the medical history and the specific facts.

The purpose of this book is not to document the medical but rather to tell a story that may give insight into a question I have asked myself all my life. "Despite the odds, what contributing factors in childhood illness lead one person to survive and thrive, when others do not?"

# Part I

# Chapter 1

## A Surprise Arrival

*"There is no such thing in anyone's life as an unimportant day."*  
~ Alexander Woollcutt

Imagine a mother going into labor, expecting one premature baby and delivering two. This is my mother's story of the day my twin sister and I were born.

Let me explain. Four weeks prior to her due date of September 21, 1953, my mom unexpectedly went in to labor. Upon learning my mom's "time had come," and her bundle of joy was on the way, a gentlemanly neighbor escorted my parents to the hospital. My dad, a custom home builder, had a pick-up truck as his only means of transportation. The friend and neighbor didn't take kindly to the idea that a woman would be arriving at the doors of a hospital to give birth in what he considered to be an improper vehicle. He offered to drive my mother and father in his comfortable, shiny clean sedan.

When my mother arrived at the Women's Hospital of Baltimore, she was taken behind closed doors. My dad, the expectant father, and their "chauffeur" were ushered to a vestibule, where they sat waiting to hear the announcement of the delivery of my father's newborn child. It was an era when

women's husbands, fathers to the children, were not allowed entry into the delivery room, or birthing center as hospitals refer to them today.

No different from the majority of the childbearing women of her time, my mom was given drugs lest she feel the pain of labor and delivery.

After having delivered one "preemie," a baby daughter, the obstetrician, taken quite by surprise, announced there was a second child on the way. Three minutes later, the second premature and unexpected infant was delivered - another daughter. The babies were immediately rushed to isolettes where breathing was assisted by oxygen.

What my mom and dad saw several hours later, they described as "two little monkeys" attached to wires, monitors and tubes. Underneath the babies almost translucent skin appeared to be a jumbled mess of veins and arteries.

Born at two pounds thirteen ounces and four pounds seven ounces, my twin and I combined weighed less than one average baby in today's world of high tech prenatal care. So weak was I that our mother and father knew nothing of the twin surprise that awaited them on that day, Thursday, August 20, 1953.

Ultra sound screening was twenty-five years to thirty years away from being developed. Extensive prenatal care, genetic testing, and high-risk obstetric specialists did not exist at that time. Even my mother's obstetrician could not detect that a stronger twin sat atop a much smaller twin, whose heart beat could not be heard.

Neo-Natal Intensive Care Units were not established in hospitals until the nineteen-seventies. Hospitals were more reliant on the loving care and hands of the nurses than the equipment, instruments and sterile conditions that exist in NICUs today.

During my mother's pregnancy, a name for a daughter and son had been decided. With the surprise arrival of two daughters came the need for a moniker for the second child. Our parents felt their two little girls should have two little

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names and so it was agreed we would be called Sue Anne and Jan Lee.

When our Uncle King, our mother's brother and only sibling, was told the names of his two new nieces, born of Irish, English and Scottish heritage, he stated in his legendary humorous way, "My God, you must have given birth to two Asian twins with names like that!"

I, the smallest and elder twin, by three minutes, was born with red hair and a temper and a story of my own.

## Chapter 2

# Heartstrings

*"God's plan for us is always that of grace. We just don't always like it when he says "no." Even when it's for the best."*

~ Unknown

Shortly after the birth of his two premature daughters, my dad made an urgent phone call to my maternal grandfather to come to the hospital, as soon as possible. A second phone call was made to The Reverend Bob Bradford, pastor of the Maryland Presbyterian Church, my parents' place of worship. The Reverend was urged to come quickly and to immediately perform the rite of baptism for me. My chance of survival was very slim.

The physicians advised my parents I would be unable to suckle a bottle. Therefore, they prepared to tube feed me. However, the one with the story of her own tried to prove the doctors wrong. As the doctors began the procedure of placing the feeding tube down my throat, I began to suck, causing cardiac arrest.

It quickly became apparent to the doctors there were medical issues beyond very low birth weight that needed to be diagnosed. Irregularities in the almost inaudible heartbeat were detected, and the doctors and nurses could feel no pulse

in my ankles. Extensive x-ray and electrocardiogram testing indicated a pinched aorta, a rare abnormality of the heart. This final diagnosis was a death sentence in and of itself. Heart surgery had seldom been performed before successfully to correct such a condition.

In the nineteen-fifties, a mother's hospitalization after having given birth was about a week's time. A week went by and my mother prepared to go home. Below the five pound minimum weight required to discharge newborns, the child my parents had been preparing to accept into their marriage and life was unable to leave the hospital along with their second unexpected delivery from God. Leaving the hospital empty handed, my mother was attached to two premature babies only by heartstrings.

Visitation to the hospital to check on my sister and me and to consult with pediatric doctors became part of my parents' daily routines. Uncle King and both sets of grandparents joined the watch. Visiting us as often as possible, they were unable to touch my sister and me due to the risk of spreading germs to our fragile bodies, so they peered through the glass window into the nursery.

After many medical tests and evaluations, our parents were advised that my cardiac abnormalities were not found in my sister. Other than low birth weight Jan was healthy and without medical issues. Her release from the hospital was solely dependent upon her reaching the five pound weight requirement. Steadily Jan began to gain weight and within four weeks time, the day came when she was taken home, leaving me all alone in the hospital.

Although elated to have one of their twins out of the hospital, my parents' concern and anxieties continued. The possibility of subsequent heart failure persisted hour by hour, day after day and with each feeding. My parents realized it would be many months before I would join their household, if ever at all. Only able to consume one or two ounces of nourishment at a time, my weight gain came very slowly.

Dr. Milton Markowitz, a pediatric specialist and cardiologist from Johns Hopkins Hospital in Baltimore began to consult on my heart anomaly referred to as "coarctation of the aorta - the narrowing of the major artery carrying blood flow out of the heart to the extremities of the body." The doctors discovered the coarctation was the reason the pulse in my ankles could not be felt.

Successful cardiac surgery in the early nineteen-fifties was in the infancy of development. Until that time, the majority of those with cardiac abnormalities lived their lives without the intervention of medicine, only at God's will.

If I were to survive my early days of life, my heart would continue to enlarge if left untreated. Time, Dr. Markowitz advised my parents, was needed to study and plan on how surgeons might be able correct the pinched aorta. A successful result would be partially dependent on "proper timing." It was critical not to let the heart become so enlarged it would become what the cardiologists referred to as a "beef heart." The physicians' hope was that my enlarging heart would retain some of its elasticity and return to some semblance of normalcy in size, post surgery.

Waiting and watching was the doctors' plan.

## Chapter 3

# Double Trouble

*“Let our advance worrying become advance  
planning and thinking.”*  
~ Winston Churchill

Three months went by. Between the busyness of taking care of my sister, my parents continued to return almost daily to the Women’s Hospital to observe and spend time with me. At that time, interstate highways and good roads had yet to be built. The trip from the suburbs of Baltimore to the inner city was not as easy as it is today, probably an hour and a half each way, depending upon traffic. In those days, people stayed closer to their own neighborhoods and didn’t frequently drive those kinds of distances.

Finally, the day came when my parents were able to hold their first born baby. For three months, I had only known the tender care of the nurse’s hands. My parents and I were no longer connected only by sight through the clear glass walls of the isolette.

As I slowly began to gain weight, a plan for my release from the hospital began to take place. Not sure how they would juggle the demands of feedings, bathing and diaper changing of two infants at once, my parents had many sleepless nights. Clearly, if I survived, my care would be more than that of an

ordinary newborn baby. Frequent feedings in tiny amounts would be necessary to sustain me. The extra energy required to eat stressed my tiny body, so cardiac arrest was still of grave concern. Survival would depend upon very watchful and careful parenting.

My mother's quandary of how to handle two premature babies while my dad was at work was greatly relieved when a friend and neighbor called to say help might be available. There was a woman in the area looking for work.

"Who is the woman? How old is she and is she married? Does she have any credentials or experience with premature infants?" my parents inquired.

Her background information was limited and shockingly unexpected. She had been living in a mental institution, admitted as a young girl when her parents were unable to care for their large brood. There were too many mouths to feed. Adoption facilities were too over-crowded, so the alternative was to put her in a sanitarium where there were beds available and she could be properly fed and cared for.

Now at an age when the girl could work and contribute economically to support herself, she was being released. The questions about her age could not be accurately answered. The records at the sanitarium were shabbily kept.

The woman's niece had signed a form saying she would take responsibility for her aunt.

My parents continued to ask many questions that in this day and age you are not allowed to ask when hiring. They gave thoughtful and prayerful consideration to their decision.

"Perhaps we ought to give her a chance," my father said.

"Yes," my mother conceded. "We need to trust that God has put this person in our path for a reason." A decision was quickly needed; my homecoming day was just around the corner.

What my parents did know for sure, was with two tiny babies, one living on the edge, they'd need assistance if my dad was going to be able to work and support our family.

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When the woman arrived for her first day of work, my parents learned that the set of hands that they had hired to help with cooking, laundry, tending children and cleaning were those of an African-American woman named Fanny.

## Chapter 4

# And the Beat Goes On

*"The strength in love is shown in great things;  
the tenderness of love in little things."*

~ Robert C. Chapman

Now that I was home from the hospital, there was something my parents still needed to set right. They wanted to make a promise and acknowledgement to God that Jan would also be raised in a home of Christian love. With tiny me in tow as a witness, my sister was baptized at the Maryland Presbyterian Church.

My parents found their own rhythm in their daily lives with twins. Jan found regular patterns of waking, sleeping and eating. However, for me, nourishment still came in very small and frequent feedings. My mother and father alternated spending all nighters in the rocking chair keeping me comfortable, taking turns with the struggles that came with getting me to eat and sleep, ever watchful for cardiac arrest as I ingested wee amounts of food. For me, life was uncertain and fragile.

The godsend of a third set of hands allowed my dad, along with his crews, to continue his career of building custom homes and a few churches in and around the growing post-war suburbs of Baltimore.

One such project was the construction of an addition to the Maryland Presbyterian Church, where my parents were charter members. The addition became the new sanctuary and meeting house, complete with kitchen and Sunday school rooms. The beginnings of my Christian faith began in that church.

Physicians continued to document my health as six years passed. I have little recall of those years, except for an occasional memory of sitting in doctor's waiting rooms with my mother. She'd try to entertain me as we sat, reading aloud the "Highlights for Children" magazine that was so popular in pediatric doctors' offices during that era.

Consulting on my case was a Johns Hopkins resident doctor from Iran, Dr. Pijay Sharif and Dr. Henry Bonson. Bonson was a young man who had studied under and with the Tausig-Blalock team that developed the surgery for "blue babies." Discussions grew more serious about how to perform heart surgery to give me a chance at having a long and fulfilling life. The doctors began "practicing" the procedure on noodles. When cooked, the noodles resembled the consistency of the artery that they were about to repair. They snipped and sewed, snipped and sewed, getting used to the feel of working with slimy, wet pasta.

My Uncle King and others in the church and neighborhood began donating pints of blood in preparation for the many transfusions needed to perform my surgery. My uncle also made a decision to be on the observation deck in the operating arena. Cardiologists and students of medicine from Johns Hopkins witnessed and learned from my surgery.

When I reached six years of age, and twenty-five pounds, the doctors felt the timing was right. The cardiologists had determined they needed to act before my heart grew any larger, hoping that I was strong enough to withstand the five hours of heart surgery.

Finally, the day that started a new chapter in my life came for my parents and me. The pioneers, the surgeons at one of

the finest medical teaching universities in the country, Johns Hopkins, were prepared to take on the co-arterctation surgery. The year was 1961. I had just begun my seventh year of life.

My mother recounts her memory that as she and my father crossed North Wolfe Street and carried me through the hospital doors, "she felt the presence of her deceased Mom holding onto her arm as she and my dad walked the walk."

My fate was in the hands of the practiced surgeons and at the grace and will of God.

All she and my dad could do was pray.

## Chapter 5

# A Child's Way of Thinking

*"Every man's memory is his private literature."*  
~Aldous Huxley

When I awoke from my surgery, apparently, according to my mother, I was furious at my father. To my childish way of thinking, I felt it was my dad's fault that I had been hospitalized and a surgical procedure had to be performed. My mother relates that "my anger toward my dad was easily soothed and dissipated by the gift of a huge, soft pink stuffed animal." I do remember the day when my dad brought the bunny to me as I lay in the hospital bed. It was so large it made me feel like Alice in Wonderland. The stuffed animal sat upon my bed for the rest of my childhood days.

I have little recall of the medical details that came with my hospitalization and heart surgery in 1961. As if I were given a pill so I would forget, from that point onward, I was able to move ahead. I've lived my life nearly free from the memories of the testing, examinations, pokes of the needles, transfusions, wires, monitors and more that went along with the operation.

Heart surgery during the nineteen-sixties was invasive. I have a small permanent physical scar in the bend and crease of my elbow, where tubes were inserted for many blood transfusions. A very thin scar, now less than the width of a

piece of string beginning under my arm, wraps around to my back, and up to my shoulder blade. The surgeons had to “cut me in half” to perform the work that saved my life.

Other memories from those days include receiving heaps of letters, cards and crayon drawings from first grade classmates, neighbors and family wishing me well. My parents brought the correspondence to the hospital to read to me, as I had not yet mastered the art of reading since I had only been in first grade a few weeks time.

As a gift, I received a rabbit’s foot from a concerned family in the neighborhood, which was discovered to be troublesome. My eyes and nose ran, as I rubbed and rubbed the soft and soothing fur of the lucky talisman under my nose and on my face causing me to sneeze and sneeze. My parents and the doctors said “it must go.”

Every year as I watch life spring forth in my gardens, I think of the half dozen or so nineteen-fifties style flower vases that I was surrounded by in the hospital bed that year. They were shaped like puppy dogs, kitty cats, charming little girls and pretty garden hats, filled with colorful flowers. The posies long gone, the containers sat on the bookshelves in my childhood bedroom for more than thirty years. It wasn’t until my parents moved out of our last childhood home, to an island on the eastern shore of the Chesapeake Bay that I let them go.

My sister and I remember receiving a gift meant for both of us, before I left home for the surgery: two tiny live aquatic turtles, called red eared sliders, and a glass bowl to keep them in together. The turtles became my sister’s responsibility while I was in the hospital. It was her duty to keep them alive. It is interesting to note, as I have come to learn today, that turtles possess an enviable and god-like resistance to aging. They symbolize longevity.

We both also nostalgically recall receiving a box of licorice candies, resembling over-sized Good and Plenty. The hard candy-coating was decorated like babes swaddled in pink and blue blankets.

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My mother tells a story of bringing a nineteen-fifties turnstile record player to me in the hospital with forty-five rpm records of children's songs and rhymes, among them *The Little Engine that Could*. She recounts her memories of walking into the hospital room and catching me pushing the record around the turn table with my toes. Tethered to medical paraphernalia, I couldn't reach the end of the bed to turn on the record player. As my healing in the hospital bed began to take place, I needed to hear the words *I Think I Can, I Think I Can*. The nurses and my parents continually repeated this phrase to me as I grew stronger every day.

As an adult I have revised those words. Whenever I doubt myself, I repeat "I Know I Can, I Know I Can." It has helped me in countless situations.

A wondrous gift from God became part of our family life. I believe this present along with my parents, and the doctors and nurses that attended me were all key to my emotional recovery.